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Ethical Deception? Responding to Parallel Subjectivities in People Living with Dementia

## Ethical Deception? Responding to Parallel Subjectivities in People Living with Dementia

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### Abstract

*Many caregivers feel that they need to lie or withhold the truth from people living with dementia, but worry that, in doing so, they are violating a duty to tell the truth. In this article, I argue that withholding the truth from and, in limited circumstances, lying to people living with dementia is not only morally permissible, but morally required by a more general requirement that we treat each other as persons worthy of respect. I do so through an analysis of the groundings of the duty to tell the truth, and a critical reflection on its cognitively ableist construction.*

### Introduction

How should I respond when I know somebody is mistaken or working off of

incorrect information? The intuitive answer many of us would reach is that, barring exceptional circumstances (for instance, that doing so might put me at risk of harm), I should correct this person's errors and inform them of the truth. This is a positive duty to correct the erroneous information of others, but there is also a correlated negative duty not to give or add to false information: not to lie. Indeed, refraining from lying is seen by many political and moral philosophers as a fundamental value. Immanuel Kant, perhaps the most famous philosophical opponent of lying, believed in an absolute prohibition on lying; in part justified by his notion of the categorical imperative which, in its simplest form, is the view that we should only pursue actions that could be adopted as a universal rule [1](#). From Kant's point of view, a universal law that said it was permissible to lie would be entirely self-defeating, as people would cease to believe one another and communication between persons would break down [2](#).

Whatever the merits of this particular argument - I do not wish to directly challenge Kant here - I invoke it only to illustrate the foundational importance of truth-telling in moral and political philosophy. In what follows, I trouble this view by asking what we should do when people living with dementia act on information which we know is erroneous but we know we cannot dissuade them from. My contention is that withholding the truth from and, in limited circumstances, lying to people living with dementia is not only morally permissible, but morally required by a more general requirement that we treat each other as persons worthy of respect. I use the term 'truth-telling' as an umbrella term for the two duties I have mentioned: the negative duty not to lie and the positive duty to correct erroneous information. In the interests of simplicity I will use the term 'lying' to refer to breaking either duty except in cases where it is necessary to distinguish between them.

In section 1, I argue that, while truth-telling is instrumentally valuable in many different ways, its only intrinsic value is in respecting the object of truth-telling's status as a person worthy of respect. In section 2, I introduce the idea of a parallel subjectivity to describe the persistent erroneous beliefs held by many people living with dementia from which they cannot be dissuaded and, via insights from scholars in disability studies, I argue that the idea that truth-telling always respects the status of persons is a cognitively ableist construction that implicitly devalues the lives of people living with dementia. Finally, in sections 3 I propose a practice I call 'ethical deception' as a technique for responding to parallel subjectivities in people living with dementia.

## Section 1: Why Tell the Truth?

Why might we think that there is a duty to tell the truth? Answers to this tend to depend on context. For instance, in a doctor-patient interaction we might think that the doctor should tell the truth to their patient because it will allow them to make the right choices [3](#). In a teacher-student interaction we might think it is important for the teacher to tell the student the truth because doing so will enable them to flourish into an autonomous being in the future [4](#). In a parent-child interaction we might think that truth-telling is necessary in order to ensure that the child's relationship with their parent is one of trust and mutual understanding [5](#). The reasons I have given here are all *instrumental values* of truth-telling, which is to say that they present truth-telling as a means to achieve some important end.

Instrumental values are important, but they can be weak because there may be some situations in which we can achieve the value without the action we are seeking to understand. In each of the interactions listed above, for instance, we can achieve the goals that I presented to demonstrate the instrumental value of truth-telling, without telling the truth. Let us start with the question of the doctor-patient interaction and add some more detail to explain this point

*The Smoker:* Dr Jessop wants her patient, Jim, to quit smoking. She has tried to inform him about the likelihood of him developing terminal or chronic illnesses but he does not seem to care that much about them. She suspects that he is not taking the risks seriously. One day he visits Dr Jessop with a complaint of pain in his throat. She knows that this is a particularly nasty viral infection that will get better without medical intervention but she spots an opportunity to assist Jim in making the right decision. Instead of telling him the truth, she tells him it could be the start of esophageal cancer and that he ought to quit smoking right away to prevent it developing.

Most of us would believe Dr Jessop has acted unethically here. Ignoring any practical considerations that might derail this case (let's assume Dr Jessop knew Jim does not really understand how cancer works and would not research his symptoms), it seems that even though Dr Jessop is assisting Jim to make the right decisions about his health, she has mistreated or even harmed him by telling him that his comparatively minor health complaint is in fact something much worse.

Some important value has been transgressed here and it does not seem to be an instrumental value. The case is not perfect; for instance, it could be the case that Dr Jessop has harmed Jim by making him feel fear when he need not have – but of course the problem is he should be afraid of his risk of cancer. Regardless, if we can strip away all the instrumental disvalues in this case, we will be left with an intrinsic disvalue that should become apparent through discussing the other interactions. Consider next the teacher-student interaction.

**The Aspiring Footballer:** Mr Hall has a secondary school student who is highly gifted at mathematics. He sees the potential in this student to take his mathematical skills to great heights and to be highly successful in later life. He wants to ensure that this student is educated properly in mathematics, but because he is on the school football team he is permitted to leave his lessons early to train. Mr Hall knows that this student loves football and aspires to be a professional footballer but he thinks he is unlikely to be successful doing this. In a careers discussion with this student, Mr Hall inflates the statistical likelihood of him being unsuccessful at football in order to encourage him to drop out of the team and focus on his school work.

Again, we seem to have achieved the instrumental value of ensuring that the student is properly educated, but many of us would believe Mr Hall has acted unethically in lying to his student. Of course, we might think that there is an instrumental disvalue here in that Mr Hall may have prevented his student from achieving success in football, but suppose he never had a chance anyway – many of us would believe he had still acted wrongly. What this suggests is that instrumental values are not sufficient in determining the moral value of truth-telling. There must be something intrinsic underpinning this intuition most of us have that there is a moral duty to tell the truth. I propose that this flows from the idea of respect for persons.

Stephen Darwall proposes that there is an important distinction between two kinds of respect. Where appraisal respect focuses on how we esteem others for their achievements or attributes, recognition respect is the kind of respect we owe each other in virtue of the fact that we are persons. Darwall outlines this as follows:

"Persons can be the object of recognition respect. Indeed, it is just this

sort of respect which is said to be owed to all persons. To say that persons as such are entitled to respect is to say that they are entitled to have other persons take seriously and weigh appropriately the fact that they are persons in deliberating about what to do. Such respect is recognition respect but what it requires is not as appropriate is not a matter of general agreement, for this is just the question of what our moral obligations or duties to other persons consist in." [6](#)

Darwall offers us a definition that invites us to fill in the blanks of personhood. In order to make the argument that our intuitive feeling that there is a moral duty to tell the truth consists in respecting persons, then, I need to determine that there is some special feature of personhood that guards against being lied to. Let us look at these first two cases again: the smoker and the aspiring footballer. In both of these cases, the justification for lying is essentially paternalistic: the doctor and the teacher want their patient/student to make the right decision so they lie to nudge them into doing so. One reason we might think it is wrong to lie to the patient or the student is that to do so would treat them in such a way as to communicate that they are not capable or worthy to act on accurate information. [7](#) This would fail to show them recognition respect, because our usual notions of what it means to be a person are grounded in the idea that we are capable of making our own decisions. However, if we consider the case of the father and the child, a complication arises.

**The Family Pet:** While Jack's 3 year old son is away for an organised school trip, he accidentally runs over and kills the family's cat with his car. Concerned for how distraught his son will be when he finds out what has happened and knowing the importance of trust and mutual understanding to parental relationships, he resolves to tell his son that the cat went missing.

As in the other two cases, we can see that the proposed instrumental purpose of truth-telling has been fulfilled without telling the truth. Assuming that Jack's son never finds out that the cat died in the way it did, his trust for his father will be unaltered. If Jack's son were older, say 13, our intuitions might pull the other way and lead us to believe that Jack should have told the truth to maintain their relationship of trust and understanding. Yet unlike the other cases, it is not clear that Jack has acted wrongly. To tease out this intuition, we should consider three circumstances in which it seems permissible to lie.

The first is where we permit a *pro tanto* wrongly lying, but that it is justified all things considered. For instance, if you are a government finance minister asked on live television if you think a financial crisis is on the way and you know it is but also know that saying so will cause a run on the banks and worsen/hasten it. We might think this is true in the second case, of the teacher and student, but it does not seem as if the lie Jack has told his child is a *pro tanto* wrong, because it is unclear that the child has been wronged by the lie. The second case is that the person being lied to has forfeited their claim to the truth. Consider, for instance, a mass murderer who asks you where their intended victim is because they know that you know. Here the murderer is wronged by you withholding the truth from them, but they have forfeited their claim to the truth because of what they intend to do with it. Again, it does not seem to make sense to say that Jack's son has forfeited his claim to the truth.

The third case, which seems more promising here, is that lying is better for the person in question than telling the truth. This is how Mr Hall and Dr Jessop might justify their lying but, for the reasons stated above, this seems objectionably paternalistic. However, in the case of Jack, we might think paternalism is appropriate: it is, after all, a paternal relationship. Yet, the fact that it is better for Jack's son to be lied to, because a 3 year old is highly unlikely to be capable of processing the fact that his father has accidentally killed the family's beloved pet, is an instrumental value: the lying is a means to an end. I want to suggest that there is a stronger, intrinsic, respect based reason for lying to his son.

Remembering that the reason why lying to the patient and the student is intrinsically wrong is that doing so fails to show them recognition respect because it fails to treat them as capable of acting on accurate information. A 3 year old actually is incapable of acting on accurate information, at least in this case, so does that mean that we cannot show a 3 year old recognition respect? It would seem that our notions of what it means to respect persons are not applicable in every case

## **Section 2: Disability Studies and the Idea of Parallel Subjectivity**

Most of us have had interactions with or have heard stories of people living with dementia holding erroneous beliefs that they cannot be dissuaded from, relating to their age, where they live, who the people around them are, what is happening,

what year it is or what they are required to do [8](#). Sometimes, most commonly in (but not limited to) cases of Lewy-Body dementia, these can be full-blown hallucinations which bear little resemblance to what we perceive as objective reality [9](#). Due to the effects of dementia on memory and sensory processing, people living with dementia live, to varying degrees, in subjective realities that are parallel to the objective world [10](#). This is sometimes referred to, somewhat patronisingly, as people living with dementia living in their "own little world".

Like the case of the 3 year old child, it seems that people living with dementia (at least those advanced enough to experience a parallel subjectivity) are also not capable of acting on accurate information (at least not all the time). If we were to follow a simple rule that respect for persons requires always telling them the truth, we would presumably think that we had a positive moral duty to continually correct these erroneous beliefs or at least a negative duty to not reinforce them by lying, but this seems to trouble our intuitions about how best to treat people living with dementia. Consider the following case:

*Nicholas:* Nicholas lives with Alzheimer's disease and is resident in a dementia unit which has a keypad locked door to the outside. He is mobile and has no insight into his condition or where he is. Every day he tries to get out of the unit saying he wishes to go home and see his wife (deceased) and family. He knows where his home is and he still owns it, but does not know how to get there from the dementia unit and is likely to get lost on the way.

Telling Nicholas the truth has obvious instrumental disvalue. Learning that his wife is deceased, his children are grown and he has dementia so is no longer able to look after himself could be emotionally devastating – if he believes it to be true. On the other hand, his belief could be so steadfast that he does not believe a carer telling him the truth and thus doing so only has the effect of degrading the quality of the relationship between the carer and the person living with dementia, which is vital to the experience of dementia. Beyond all of this, Nicholas will likely not take on board this information because of the effects of Alzheimer's on the memory, so carers will need to continually have this conversation with him. I want to suggest in this paper, however, that beyond practical considerations, telling the truth to someone living with dementia who has this type of parallel subjectivity fails to show them recognition respect, because it fails to respect them for the *type of person that*

*they are*, which is to say as a person who cannot process new information easily and retains erroneous information that is subjectively consistent.

Darwall anticipates some of this, when he talks about respecting people in the roles they present themselves in: "to fail to take seriously the person as the presented self in one's responses to the persons is to fail to give the person recognition respect as the presented self or in that role." [11](#) However, insights from disability studies on the way that our notions of how best to treat disabled people are constructed from the perspective of an able-bodied person are vital in understanding why telling the truth in this circumstance is disrespectful.

Consider, for instance, Simi Linton's insights on the language of overcoming disability. Linton argues that this language is often shrouded in ableist assumptions about the ability to become less impaired through sheer willpower. She suggests instead that what most disabled people need to overcome is the social stigma of being disabled [12](#). The same language of overcoming is at work when discussing people living with dementia and truth-telling. The impairment of memory difficulties and the associated creation of parallel subjectivity are not going to be overcome through sheer willpower and the relentless repetition of difficult facts. If we demand truth-telling to people living with dementia in all circumstances, we demand an erasure of their particular perspectives and view them only through our own cognitively ableist standpoint.

Consider also Tom Shakespeare's view that caring relationships in dominant discourse are conceptualised in terms of the inadequacies of the receiver of care [13](#). Rather, he suggests, we ought to look at broader social relations which undermine and exclude disabled people, leading to a necessity of care [14](#). Viewed from this perspective, we might think of the norm that people ought to be told the truth, corrected when they have erroneous information and not lied to as a social practice that undermines and excludes people living with dementia, because it assumes an able-minded person capable of working off of accurate information. We could, instead, begin from a perspective that views the disconnect between the objective world and the person living with dementia's parallel subjectivity as something we can solve by entering into, reinforcing or just simply validating the person living with their subjective experience.

Consider, finally, Tobin Siebers' view that the disabled body troubles our



conceptions of the body more generally, arguing that viewing particular bodies as defective has the effect of casting them as less real. <sup>15</sup> He concludes by saying that the disabled body is no more real than the able body and no less real. Could we not say the same thing about the impaired mind? It seems that the subjectivities of the people living with dementia are no less real than the objective reality we experience and that this mismatch is something we can better solve by making the world more consistent than trying to make their minds more consistent.

### **Section 3: Toward an Account of Ethical Deception**

In practice, responding to the parallel subjectivities of people living with dementia requires deception. If we think we can never show respect to someone by lying this puts us in a harrowing dilemma of choosing between respecting a person and doing what is best for them. With our new respect-based defence of engaging in deception of people living with dementia, however, this dilemma disappears and we can begin to build an account of ethical deception. It is important, at this point, to pull apart the positive and negative duties. Although we show respect for people living with dementia by withholding the truth, we may harm them by telling them a lie. If, for instance, we tell Nicholas his wife is alive but then proceed to, at least from his perspective, keep him from her. It is therefore necessary, in order to ensure clear moral guidance is given to carers, that a priority ordering of techniques of ethical deception is made. I propose that it should be as follows:

1. *Ethical deception by omission*: the carer omits to give the information which is inconsistent with the person living with dementia's subjectivity.
2. *Ethical deception by distraction*: the carer distracts the person with dementia with something banal in order to avoid the clash between subjective experience and objective truth.
3. *Ethical deception by immersion*: the carer attempts to alleviate the confusion of the person with dementia by giving answers that are consistent with the subjective worldview that they are inhabiting.

Consider how this would play out in the case of Nicholas. In line with the ordering of priority, we would first expect carers to attempt to tackle this case through the use of *ethical deception by omission*. However, here simply omitting to give information that will compromise Nicholas' subjective viewpoint would not be effective unless

significant resources were available. Nicholas could be taken back to his house, accompanied by a carer and spend some time there in order to sooth his longing for his wife and children. This would not require the carer to deceive in any other way than omitting to give Nicholas the information that his wife is deceased and his children are grown up. A carer might have some success in asking Nicholas how old he is, hoping to prompt some memories that would reorientate him, but this is not always effective and the information may not be retained [16](#).

Where limited resources exist, the need to show Nicholas recognition respect demands that , if Nicholas is to be prevented from leaving the unit, he is prevented from doing so in a way that does not contradict his belief that his wife and children are waiting for him at home. A carer might therefore use *ethical deception by distraction*; offering him a cup of tea and sparking up a conversation about his children or his wife; prompting him to remember things, which might also have the effect of orienting him in time and space more.

Where a carer has attempted to use distraction in order to avoid contradicting the world he is inhabiting and it has failed, *ethical deception by immersion* becomes the only possible way of responding to Nicholas in a way that shows him recognition respect. This could take the form of telling him his children are at school, that they are on holiday, that there are no buses running today or perhaps that he has got the day wrong and it is tomorrow that he is expected at home. These techniques are used frequently by carers but there is still some question over their moral validity and applicability in care [17](#). By reframing this discussion in terms of showing recognition respect for Nicholas, the validity and limits of their application become clearer.

Applying the social model of disability to cognitive disabilities has caused some controversy in moral philosophy, Jonathan Wolff, for instance, is concerned by the practical implications of changing the world to be more inclusive because of the burden such a transformation in our society would cause to others (one particular concern is how contract law would have to change), [18](#) but in this case we are simply demanding that carers and family members rethink how they respond to erroneous information, which surely is not too burdensome.

## Conclusion

In this paper I have questioned the idea that respecting someone always means you must tell the truth to them. In fact, when people living with dementia live through parallel subjectivities, doing so can actually be disrespectful. Through the combined insights of political philosophers and disability studies scholars, I have argued that respect requires us to consider changing the world to fit the perspective before we try, usually in vain, to fix the perspectives. This has important practical implications for how carers discharge their duties and may require a level of creativity and imagination that poorly staffed care-facilities will find difficult to encourage or make time for. If this can encourage better funding and better staffing, so much the better.

It must be noted that I have only applied my proposal of ethical deception to one, particularly simple, case. The situations that carers and family members deal with can be infinitely more complex, particularly with rarer kinds of dementia, such as the Lewy-body and fronto-temporal variants. Discussing how to show recognition respect in complex scenarios would require their own papers and their own analysis. However, if the idea that we sometimes show recognition respect to people by withholding the truth presented in this paper holds, then this will provide a foundation on which to build solutions to more complex cases.

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